



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission to the Department of Social Protection on
Statement of Strategy 2015 to 2017**

August 2016



1. Introduction

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input into the Department of Social Protection Statement of Strategy.

The Department of Social Protection provides a range of payments and supports for people with dementia, including State pensions and illness and disability payments, such as Illness Benefit, Disability Allowance and the Invalidity Pension. Workplace supports and payments to facilitate participation by people with disabilities in the labour force include the Partial Capacity Benefit and the Wage Subsidy scheme. In addition, Carer's Allowance or Carer's Benefit and the Respite Care grant exist for family carers.

The demographics of an ageing population will mean that social protection will continue to play a significant role in enhancing the quality of life for the population of Irish people living with dementia and their families and carers.

The world's population is rapidly ageing, with the proportion of people aged over 60 years expected to double from 11% to 22% between 2000 and 2050 (WHO, 2012¹). While this increased longevity is a cause for celebration, it also presents a societal challenge to maximize the health, functional capacity, social security and participation of older people (Donnelly and O'Loughlin, 2015²). Ireland like much of the world is experiencing unprecedented ageing of its population, for example³, life expectancy is now 78.7 years for males and 83.2 years for females, above the EU average of 75.5 years for men and 82.1 years for women.

While dementia is not a normal part of the ageing process, age is the main risk factor. Therefore, the number of people living with dementia will increase alongside population ageing. There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals⁴. If current trends continue this will increase to 68,216 people by 2021 and to 132,000 people by 2041 (Cahill, S. & Pierce, M, 2013⁵). There is not a community in Ireland unaffected by dementia as the vast majority of people live at

¹ World Health Organisation (2012) Dementia, A Public Health Priority. Download from: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

² Donnelly, S. and O'Loughlin, A. (2015) Growing old with Dignity. In A. Christie et al (eds) *Social Work in Ireland*. Dublin: NCPop and UCD.

³ Source: HSE (2015) Planning for Trends and Priorities to Inform Health Service Planning 2016.

⁴ Department of Health (2014) National Dementia Strategy. Download from: <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

⁵ Cahill, S. and Pierce, M (2013) *The Prevalence of Dementia in Ireland*. Genio Dementia Learning Event.

home (63%⁶). Although the main proportion of people who have dementia are over 65 years, as age is the main risk factor, there is a significant group aged under 65, an estimated 4,000 people, many of whom are in their 30's and 40's.

In addition, many of those caring for people with dementia are older people. Research suggests that 84% of those in a caring role are over 45 and that 37% are over 65 (ASI, 2007⁷). Changing demographics of families mean that women, who traditionally performed most caring roles, are now more likely to be working outside of the. The overall number of family carers in employment has increased from over one-third to over a half in the past ten years and this number is continuing to rise. In addition, in the current economic climate, financial demands on families are likely to grow, meaning that they will find it increasingly difficult to afford to provide care (Care Alliance Ireland, 2015: 42⁸).

These projected increases present significant health, social and economic challenges for policy and planning, with implications for ensuring that people living with dementia and their families and carers are protected through access to income supports and other services that enable them to actively participate in society.

2. Comments on DSP Statement of Strategy Objectives

It will be important that people living with dementia and their families and carers are considered throughout the Department of Social Protection (DSP) strategy across the three strategic objective areas and the associated high level strategies:

Objective 1: Put the Client at the Centre of Services and Policies

ASI welcomes this person-centred objective and recommends that dementia be considered in social protection supports and services for people with disabilities from the point of information provision, access to supports and outcomes from services and supports. There are a number of key considerations to ensure that the services and supports provided by the

⁶ Ibid.

⁷ The Alzheimer Society of Ireland (2007) Living with Dementia – The Experience of Carers with Dementia (unpublished)

⁸ Care Alliance Ireland (2015) Family Caring in Ireland. Available via <http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf>

DSP enhance the lives of people living with dementia and their families and carers. These include:

- Better awareness and understanding of dementia in the DSP.
- Information and advice services to take account of dementia.
- A focus on the specific needs of people living with dementia under 65.
- Improved access to supports and services for people living with dementia and their families and carers.

Awareness and understanding of dementia

A greater understanding of dementia is required among staff within the Department of Social Protection. The National Dementia Strategy has a specific action referring to staff in frontline public services:

The Department of Health and the Health Service Executive will consider how best to promote a better understanding of and sensitivity to dementia among staff of frontline public services, as part of the Health-Promoting Health Service Executive Initiative (NDS, 2014: 18).

In addition to the NDS action on raising awareness and understanding of dementia, the ASI is leading a Dementia Friendly Communities (DFC) initiative that aims to transform villages, towns, cities and communities into better places to live for people with dementia. Dementia Friendly Communities seek to encourage more collaboration between nongovernmental organisations (NGOs) and local services, and ensure that there is a better awareness, understanding, and sensitivity throughout the local community about the needs of people with dementia.

Improved financial information, advice and guidance

People living with dementia and their families and carers may need extra time when applying for services or supports or when accessing information and advice. As stated

above, this requires a greater understanding of dementia among staff but it also means their needs are considered in the provision of information, advice and guidance.

The financial impact of giving up work can have a specific impact for people with early onset dementia who are more likely to have financial commitments and dependent children. People with dementia and their families should be appropriately referred to state agencies such as the Money Advice and Budgeting Service for financial information, advice and guidance.

Specific needs of people of working age living with dementia

The Department of Social Protection should consider the needs of people aged under 65 living with dementia when developing workplace supports and education and training programmes for people with disabilities. In addition, employers must be supported to facilitate people aged under 65 living with dementia if they continue to work after diagnosis.

For people who cannot work and are under 65, there are specific financial issues. For example, a younger person with dementia may have to give up work but may still have a family to support and a mortgage etc.

Access to supports and services

The DSP can play a significant role to ensure that the correct supports are available to people living with dementia and family carers of people with dementia who also have support needs when trying to balance work and care.

Yet, people with dementia and their carers have informed ASI that they often struggle to access their entitlements. This can be the result of poor staff training and inappropriate assessment processes that do not capture the specific impact of dementia on a person with dementia's life, ability to work, income and other support needs. It can also be the lack of flexibility of DSP services as carers of people with dementia have highlighted the need to access support services outside of normal working hours. This increases isolation and pressure on working carers.

Objective 2 Drive Cost, Efficiency and Effectiveness

ASI acknowledges that this specific objective refers to outcomes for processes and procedures as well as referring to inter-agency working. Inter-agency working across the DSP and Department of Health will ensure that greater efficiency has a positive impact for people living with dementia.

It is important that application processes and procedures must accommodate the specific information and communication needs of people living with dementia. All efforts must be made by the DSP to comply with the Assisted Decision Making (Capacity) Legislation, which will mean that more people living with dementia will be supported to make decisions rather than have decisions made in their best interests.

It will be important that cost effectiveness and efficiency is underpinned by principles that respect the rights of clients such as people living with dementia. The Irish Dementia Working Group⁹ in collaboration with the Alzheimer Society of Ireland has developed a Charter of Rights for People Living with Dementia, which is a valuable resource for staff and policy makers¹⁰.

Objective 3 Develop Staff, Structures and Processes

As stated earlier, better awareness and understanding of dementia will benefit staff, structures and processes throughout the DSP to the benefit of DSP clients living with dementia.

In addition, disability and equality proofing streamlining processes will ensure changes benefit the most vulnerable DSP clients. There are tools available from the Irish Human Rights and Equality Commission as well as the disability proofing guidelines developed by the Department of Justice and Equality.

⁹ The Irish Dementia Working Group is a national advocacy group which has been involved in development and influencing work since February 2013. The working group is resourced and supported by the Advocacy and Public Affairs team at The Alzheimer Society of Ireland.

¹⁰ <https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx>

3. Comments on DSP Statement of Strategy Priorities

There is a concern that the three priority areas as outlined, do not consider those DSP clients not in a position to work or be activated for employment. It is important that a priority area includes reference to improving living conditions for those unable to work. In the ASI's experience working closely with people with dementia and their family carers, we see a financial hardship as a result of living with dementia. This is because there are significant costs associated with living with dementia and since dementia is a progressive condition, the type and level of care a person needs will change over time, potentially changing on a day-to-day basis. Medical costs can include prescription charges and medication costs or personal care supplies but there are also indirect costs such as living expenses, transport, income and finances, medical needs and medications. Research in Ireland by O'Shea (2000) highlights the additional weekly costs incurred by carers arising as a direct consequence of their caring role¹¹. These included additional expenses relating to eating, transport, and their own personal care and health. A carer, when speaking about the financial impact of living with dementia¹², which informed a previous ASI submission stated:

'I cannot work as much as I need to be at home more and provide care, but I am also buying more as she [referring to her mother she is caring for] needs more things like using more bed clothes even costs money'.

When unable to work due to the disabling aspects of dementia for a person themselves or for their family carer(s), this population of DSP clients must be supported to continue to participate in society.

4. Conclusion

The ASI welcomes the opportunity to input into the Statement of Strategy. The needs of people living with dementia and their families and carers must be incorporated into DSP objectives and this can be achieved by developing a better awareness and understanding of

¹¹ O'Shea (2000) The Costs of Caring for People with Dementia and Related Cognitive Impairments. NCAOP. Available via http://www.ncaop.ie/publications/research/reports/60_Costs_Dementia.pdf

¹² Please see the ASI website for further submissions informed by carers and people living with dementia <http://www.alzheimer.ie/about-us/policy/policy-submissions.aspx>

dementia in the DSP; ensuring information and advice services take account of dementia; developing a focus on the specific needs of people living with dementia under 65; and generally improving access to supports and services for people living with dementia and their families and carers. Addressing dementia requires a whole of government approach and closer inter-agency working with the Department of Health will ensure that people with dementia are supported to live well and participate in their community with accurate social protection to address their income and other support needs.

About the Alzheimer Society of Ireland

The ASI is the leading dementia specific service provider in Ireland. We work across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their family carers.

Our range of supports and services include a National Helpline, Dementia Adviser Service, Social Clubs, Alzheimer Cafes, Home Care, Day Centres, Respite Care, Family Support Groups, Family Education Programmes and Cognitive Stimulation Therapy Programmes. We are also the only national advocacy organisation for people with dementia and their carers.

Our vision is an Ireland where no one goes through dementia alone and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support. A national non-profit organisation, The ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

For further information, or if you have any questions or queries about this submission please contact the ASI's Policy Officer, Dr. Mags Crean on 01 2073800 or email margaret.crean@alzheimer.ie

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